

Your Health Information is at Risk- STOP Weakening the Privacy Rule



October 17, 2002

Dear Colleague:

As medical information is increasingly transmitted, accessed and stored electronically, Americans are worried about losing control over one of the most precious, private aspects of their lives – their personal health information.

According to a recent survey conducted by Princeton Survey Research Associates, 1 in 6 people in the United States has done something out of the ordinary to keep personal health information confidential, such as withholding information from their doctor, providing inaccurate information, or, in some cases, avoiding health care altogether.

On August 14, 2002, when the Department of Health and Human Services issued modifications to the December 2000 medical privacy rule, HHS deepened the anxiety that many Americans feel about the security of their health information. These modifications weakened vital protections in the rule and created dangerous loopholes that expand unauthorized access to the personal health information of millions of Americans.

H.R. 5646, The Stop Taking Our Health Privacy (STOHP) Act, puts patients' privacy first by closing massive "privacy peepholes" that HHS opened in the areas of:

1. **Consent:** The STOHP Act restores the right of patients to decide whether to permit the use and disclosure of their personal health information for purposes of health care treatment, payment and so-called "health care operations". In August, HHS eliminated patient consent in these three important cases, denying patients the fundamental right of deciding for themselves whether their health information can be used or disclosed.
2. **Marketing:** The STOHP Act ensures that patients are not unwitting victims of marketing campaigns disguised as objective medical advice. Our bill would reverse the change that HHS made to the marketing definition, which allows health providers to send unsolicited health recommendations to patients that are paid for by drug companies without informing patients of the financial connection between the company and the health provider.
3. **Disclosures to FDA-regulated entities like drug companies:** The STOHP Act narrows the purposes for which personal medical information can be used or disclosed to these entities without patient consent. Our bill limits nonconsensual disclosure to these entities for the purpose of strict public health priorities such as drug recalls. The August modifications created a broader exemption that allows nonconsensual disclosure of patient information to drug companies for a wide range of activities, which may include marketing campaigns.

If you would like to co-sponsor the STOHP Act or receive additional information, please have a member of your staff contact Kendra Bodnar at 5-2836 (Rep. Markey), Kristen Amerling at 5-5051 (Rep. Waxman), or Karen Folk at 6-3400 (Rep. Dingell).

Sincerely,

Edward J. Markey
Member of Congress

Henry A. Waxman
Member of Congress

John D. Dingell
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